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Risk owners and risk managers: Dealing with the complexity of feeding children with neurodevelopmental disability

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Short title: Risk owners and risk managers

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Abstract

This paper illustrates negotiations around risk between lay people and clinicians in relation to gastrostomy interventions for disabled children. These negotiations centre on differing interpretations of what constitutes risk in relation to the safety of oral feeding and a child's need for a feeding tube between parents, carers and clinical specialties. Drawing on Heyman's distinction between risk managers and risk owners we show that not only do clinicians act as risk managers, and parents and carers as risk owners, but that these distinctions often become blurred either because of the shifting dynamics of relations of care, or because of the specificity of clinical practice. Parents become risk managers in relation to carers' roles while clinicians become risk owners in relation to particular procedures which define their practice. This has implications for lay and expert interactions as well as professional accountability for those caring for children with complex medical conditions. Although not an empirical article we draw on empirical work in the UK. We analyse both parental and professional constructions of risk based on observations of co-ordinating a clinical trial designed to evaluate the effectiveness of gastrostomy surgery. We also examine

the diverse value systems used by different groups of professionals and lay carers which inform judgements about risk, and feeding. We conclude by arguing that issues of risk in contemporary health care are not just examples of 'manufactured uncertainty' or of 'negotiated power' but constitute a dialectical relationship which breaks down the essentialist dualism of lay and professional constructions of risk.

Key words: UK; lay knowledge; risk; infant feeding; gastrostomy; risk management; aspiration; neurodevelopmental disability

Introduction

Modern medicine is a contested terrain in terms of decision making about the appropriateness of procedures and what counts as acceptable risk. Historically the benign paternalism of clinical decision makers was seen to be sufficient, however this approach has been challenged by contemporary expectations and greater involvement of patients and lay carers in their treatment (Gabe, Olumide & Bury, 2004; Coulter 1999). What constitutes risk and how risk is managed is now seen to be more complicated but, to date, no research has focussed on how risk is defined and managed in clinical encounters by the different groups involved in the feeding management of disabled children. In this paper we draw on a number of contexts/scenarios as examples of the specificity of risk in relation to both parental and professional constructions of the safety of oral feeding in the context of some disabled children's need for a surgical feeding tube. Children with neurodevelopmental disability, such as those with severe cerebral palsy for example, are considered small compared with age standardised norms which has been attributed, in part, to difficulties achieving an adequate nutritional intake orally. (Reilly, Skuse & Poblette 1996; Reyes et al.1993; Gisell & Patrick 1988). In some cases oral feeding is considered unsafe, due to high rates of oral aspiration (that is food and secretions are transported into the airway), with implications for the child's

respiratory health, including the risk of chest infections and aspiration pneumonia (Rogers et al 1994).

This provides an arena whereby parents and professionals enter into negotiations about the child's best interests and the management of feeding including the need for a surgical feeding tube to avoid feeding by mouth where this is considered a risk to the child's health. Deciding what is in the child's best interests however is rendered particularly complex because of the role of carers/surrogate feeders across different caring contexts who also have a role in managing risks associated with feeding

This paper examines the different value systems informing evidentiary claims and knowledge positions used to inform judgements about risk, the safety of oral feeding and future treatments of disabled children with feeding difficulties. Echoing Heyman's (2010) distinction between risk managers and risk owners we show that not only do clinicians act as risk managers and parents and carers as risk owners, but that these distinctions often become blurred because of the shifting dynamics of relations of care or because of the specificity of clinical practice. In this way parents become risk managers in relation to carers' roles, while clinicians can become risk owners in relation to particular procedures which define their practice. A central argument developed in this paper is that whereas some groups of clinicians manage risk underpinned by the logic of formal tests and investigations designed to highlight pathology, parents broadly manage risk in the context of their everyday lives underpinned by the logic of 'normalisation'. However these positions can reverse in a number of different scenarios which reorganises our understandings of risk and the resulting treatment options.

Research context

This is not an empirical article, although it draws on empirical work; rather it seeks to develop ideas about risk owners and risk managers. We utilise a study of professional and parental interactions that occurred at specific points in the patient referral pathway during the course of a research study evaluating the effectiveness of gastrostomy feeding interventions

coordinated by one of the authors (reported in Craig et al 2006). We draw on observations of clinical consultations following a referral for gastrostomy and referral letters in patients' notes, in addition to interviews with parents (reported in Craig 2004; Craig, Scambler & Spitz 2003). Specific scenarios or contexts where there were disagreements about the meanings of tests and investigations or children's feeding management were recorded in a reflective journal (compare Lincoln & Guber, 1985). This data has been reworked for the purpose of this article. Although the examples presented are not necessarily exhaustive, nor meant to be representative, they were chosen specifically to illustrate our ideas. As such the scenarios were selected for a purpose and their significance reflects those aims.

Approaches to Risk

Debates about risk have moved on considerably since the seminal contributions of Beck and Giddens in the 1990s. Beck, in particular, used risk to situate his idea of a second modernity in which a 'revolution by side effects' (Beck et al., 2003) has occurred leading to a 'normativity of diversity' which undermines traditional power structures and assumptions about the life course, institutions and the family (Beck, 2007). What Beck is pointing to is, to use Giddens's term, 'manufactured uncertainty' in which experts and lay people have to negotiate over processes of an increasingly individualised world where ownership and management of risk are seen as both technical and moral concerns (Giddens 1991). While critics, such as Horlick-Jones (2003: p227), argue that reflexive modernisation has limited explanatory potential to 'capture the detail of specific risk related situations' we suggest that there has been a transformation of roles within clinical encounters from the classic sick role described by Talcott-Parsons (Parsons, 1951) to the more mutualistic approach of Stewart and Roter (1989) which, in part, have been aided by the democratisation of authority in society and by the availability of information technology (Webster, 2002).

Moving on to the issue of risk itself, while Wynne (1996) criticises both Beck and Giddens's realist epistemology for starting from the point of view of the scientist as expert and thereby excluding lay perspectives, we would argue that this position is also too binary in its

assumptions and that both perspectives are needed if we are to understand how negotiations of risk are accomplished within clinical encounters. More specifically we wish to investigate how risk discourses are managed and owned by different participants in a particular medical context, namely the management of disabled children's feeding particularly those children diagnosed as having severe cerebral palsy.

Risk, risk owners and risk managers

In this paper we draw on Zinn's (2008:173) definition of risk as a 'material or symbolic danger or harm, or an alleged negative future event' and therefore aim to show how uncertainty is 'rationally' managed by both clinicians and carers. We also introduce Heyman's (2010) set of distinctions between the roles of risk manager and risk owner. These distinctions were set up to understand the difference between particular risks and the general concept of risk.

Heyman argues that while it is difficult to give a specific definition to the idea of risk, given that the term is used to deal with both contingency and probability, it is still necessary to understand its role in many health and social care practices and therefore the delineation of the distinctive roles of risk manager and risk owner within these processes. Using Heyman's definition, a risk manager is: 'a formally designated professional who claims expertise in risk management' or a 'practitioner who views their role through the lens of risk' or 'any person who attempts to manage a risk' through themselves or others (Heyman, 2010: 32).

Conversely, risk owners are those who: 'take on, or are ascribed, accountability for the management of a risk'. Heyman also acknowledges that the relationship between risk ownership and management is by no means clearly demarcated (p33) and suggests an inclusive concept of risk manager is, therefore, required given the actively interpretative role of all persons engaged with the risk (p35). This definition also recognises all those who are involved as stakeholders including patients, carers and practitioners engaged with a particular risk.

We aim to use these notions of risk manager and owner and their relationship to professional staff and parents of children referred for a surgical placement of a gastrostomy feeding tube.

We show how children's feeding difficulties creates a forum for negotiation in which parents and professionals participate. We illustrate how risk is negotiated through a series of exemplars and interchanges of risk roles that participants can play in complex health and social care settings. We utilise Heyman's schema as a heuristic for understanding the relationships between professionals in the following three scenarios in order to highlight complexity in the management of risk:

- Conflicts over interpretation of risk between clinicians and parents (for example vis a vis the interpretation of tests and investigations which indicate the child's need for a gastrostomy and safety of oral feeding).
- Interprofessional constructions of risk and conflict (for example disagreements about the safety of oral feeding and the child's need for a gastrostomy within the multi-disciplinary team).
- Risk and conflict across multiple caring contexts (for example concerns about the safety of oral feeding involving surrogate feeders in community settings).

Disability, feeding and risk

A number of tests and investigations are used to assess swallowing and feeding disorders which may indicate the need for a gastrostomy feeding tube. A barium swallow¹ is carried out to ascertain whether a child has gastro-oesophageal reflux disease (GORD)². This can be done in combination with a videofluoroscopy or swallow assessment. A videofluoroscopy is used broadly to assess swallowing disorders and the risk of pharyngeal aspiration. A barium swallow can detect whether there is an anatomical reason for GORD, such as a hiatal hernia. The focus (that is which part of the anatomy is examined) and purpose of each test therefore is slightly different. Moreover, the value attached to tests and investigations may differ as a function of clinical specialism, with surgeons more likely to request a barium swallow and neurologists and speech and language therapists requesting a videofluoroscopy in addition.³ According to Prior et al (2002:255) this is indicative of how 'different forms of visibility mark out different forms of occupational practice'.

As a result of these investigations parents may be told to stop feeding their child by mouth, due to the risk of oral aspiration, and consider feeding with a gastrostomy tube, surgically placed and, prescription feeds in place of food. However the prohibition not to feed by mouth may not be consistently applied. Not surprisingly, perhaps, the recommendation of a gastrostomy can generate parental opposition (Sleigh et al., 2004) presenting an ethical dilemma for clinicians and families regarding the child's best interests, particularly where parents reject the need for a surgical feeding tube and/or the claim that oral feeding is unsafe (Craig, Scambler & Spitz, 2003).

Conflicts over the interpretation of risk between clinicians and parents.

Parents attached varying degrees of significance to the results of tests, particularly where they felt feeding in the clinic environment, where the tests were conducted, did not adequately reflect real life circumstances (that is they lacked ecological validity)⁴ as the following extract indicates:

We looked at the results of that video [videofluoroscopy] again and yeah, John was aspirating, but it was to us a totally false set of circumstances because of the apparatus, he's got to sit in a completely different position to how he normally sits [at home]. He, he was, we were going through some speech and language therapy, we use the (name of alternative therapy centre) a lot, yeah, don't know if you're familiar with that? Yeah, we've been getting on well with feeding with using sort of cups instead of bottles and what have you, you know. So we really felt we'd come on, and the video[fluoroscopy] didn't really represent too much. Every time we've had a look at the chest x-ray it's been perfectly clear. [John's father, 1/1]

Drawing on the experiential knowledge of feeding a child in the home environment, this parent rejected professional constructions of risk premised on the results of a videofluoroscopy due to the falseness of the test situation and a lack of evidence of causal effect between the risk of aspiration and the results of a chest x-ray: 'it's been perfectly clear'. Here the parent could

be described as engaging in what Hodge and Perkins (2007:116) term: 'a quasi-scientific process' of data collection which allowed parents to make judgements about their child's health status.

In seeking out a second opinion from an alternative feeding centre with a different philosophical ethos, that of maintaining oral feeding (that is normalisation), the parents called into question the 'professional competence of orthodox sources of health expertise' (Horlick-Jones, 2003:224). The additional source of information provided by the alternative feeding centre, in this case, coincided with their own world view that the child's ability to feed orally was improving which allowed them to discount the knowledge claims of the formal laboratory tests that they 'didn't represent too much'). The expert knowledge of the alternative feeding centre, and the parents own local knowledge (perception) that feeding at home was safe, were judged to be trustworthy sources of risk information and were, therefore, privileged over the hospital investigations and clinicians' framing of risk.

In another example, a community speech and language therapist wrote a detailed report advising one mother against feeding her child orally. The therapist justified her decision based on the following criteria: an absence of spontaneous sucking; aspiration due to an ineffective cough reflex and hence the child's inability to protect her airway; and, GORD which had caused the child to be averse to oral feeding. However, at the six-month follow-up meeting the mother reported that the child was eating three meals a day which, she claimed, proved she did not have a 'feeding difficulty'. Moreover, as the child had not experienced any chest infections, the mother remained unconvinced that aspiration presented a risk to her child's health. The mother continued to feed orally (she managed the risk) and turned down the offer of another videofluoroscopy to assess the safety of oral feeding. She took up the subject position of 'mother knows best', and hence was the risk manager, and resisted the medical definition of her child's problem. In this case the mother not only became the risk manager but also through her actions, the risk owner.

Although some parents rejected the assumed risk associated with oral feeding, they often agreed to the use of a range of feeding technologies such as thickeners in feeds (to avoid aspirating on 'thin' liquids) and specialised feeding utensils. Yet in accepting the need for particular feeding interventions, they were incorporating technical constructions of risk knowledge into their feeding practices, suggesting that not all expert knowledge was rejected. As Murphy (2003:443) found in her study of infant feeding, mothers did not merely endorse expertise, they redefined and relocated it. One mother for example discounted the diagnosis of aspiration on the grounds that her daughter had not experienced any chest infections, did not show evidence of distress when eating and, had gained weight. The mother rationalised that the food must have gone into the 'right place' (not the airway) and hence the risk of aspiration was minimal.

I have reduced her food at the moment because there was some concern that some of it was blocking her airway and sometimes going into her lungs but she was on a lot more (food) than she's on at the moment, and they say that some of it might be blocking her airways. But from what I've seen, of when she was on more food, she's putting on loads of weight, so I can't see how it went into her lungs without affecting her or giving her chest infection. All I saw was that she's putting on weight so it must have gone to the right place. She never coughs or splutters with us when we give her food so I assume it must be going to her stomach. [Kay's mother, 1/2]

In this example the mother accepted the clinical recommendation to use the nasogastric tube and reduced the quantity of food given orally, to the size of an ice cube, illustrating how risk was negotiated between clinicians and parents. Here the mother was the risk manager and managed the risk associated with oral feeding (by reducing the amount of food given by mouth) rather than avoided the risk altogether. In so doing she took up the subject position of 'responsible' mother within professional discourse through her selective application of expert advice (see Hundt, 2002). The clinicians remained the risk owners through negotiation about how to minimise the risk.

Interprofessional constructions and conflicts around risk

Interprofessional contexts also illustrate how the risks associated with children's feeding were managed and owned. The role of different clinical specialties in the process of referring a child for a gastrostomy procedure also highlighted how risk was discursively and differentially constructed. In one example a mother had been advised by the community speech and language therapist against oral feeding following a videofluoroscopy because of the risk of aspiration caused by an 'in-coordinate swallow'. The mother raised this with the surgeon in the outpatient clinic and asked about the possibility of repeating the videofluoroscopy. The consultant told her it was not necessary and stated that if the child's aspiration was so severe, she would aspirate on her own saliva. Here the surgeon drew on a normalising discourse in his construction of risk (that is that aspiration is a natural state which cannot therefore be harmful) which served to marginalise the risk. In the face of conflicting advice about her child's feeding management, the mother deferred to the surgeon's reasoning which, in this case, coincided with her own. A complex range of factors may have been at play in influencing the mother's decision to accept the surgeon's version of events, including: his professional seniority as a (male) surgeon, institutional factors (the advice coming from a centre of excellence) and, advice which was compatible with the mother's world view, plus the weight of evaluation of her as a 'responsible' (that is 'good') mother receiving a health service. In this scenario the mother was left to manage the risk while the surgeon owned the risk. The speech and language therapist in the community, initially charged with managing the risk, became marginalised by the shift to institutionalised power preferred by the mother who was happy to move the ownership of the risk away from the community to a specialist tertiary centre.

In a further example, two specialists, a paediatric neurologist and an orthopaedic surgeon, independently referred a child for a surgical consultation for a gastrostomy tube. The paediatric neurologist made the referral because of concerns about poor growth, aspiration and GORD which had been confirmed by the laboratory tests and described as 'severe'. The

orthopaedic surgeon requested a referral because the child needed a hip operation which could not be done until the child had gained sufficient weight. Again the professional discourses suggested that both the referring clinicians had ownership of the risk. However the mother of the child was unclear about the best way forward as, although she accepted the child's need for orthopaedic surgery, she disputed that there was a problem with the child's feeding and was generally opposed to the idea of a gastrostomy tube given that the child 'loved his food'. Here the mother was trying to manage the risk but from the perspective of the child's enjoyment of food and, hence, normalisation.

Significantly the paediatric surgeon concurred with the mother and incorporated her view into his assessment of risk given the child appeared to enjoy food, did not vomit or choke, and had only experienced one episode of respiratory infection in the previous 18 months. Moreover the surgeon was not prepared to proceed with surgery on the grounds that the child needed the weight-gain associated with gastrostomy placement for another operation. In so doing he discounted the judgement of another surgeon (orthopaedic). Here the balance of professional control (Fox, 1993) over the patient shifted from the consultants who made the initial referral, to the paediatric surgeon. However the paediatric surgeon discursively shifted the responsibility for patient care, and hence risk, back to the referring consultants through his refusal of the operation. In this example, the surgeon's definition of risk resided in his clinical judgement and not the results of the laboratory tests. What is illustrated here is a situation comprising a number of different points at which risk was owned and managed. Initially it was owned by the referring consultants and had to be managed by the mother. The decision was then jointly owned by the mother and the surgeon (not to proceed with surgery) and later returned to the original referring doctors to own and manage.

This example would suggest that not only was clinical decision making influenced by the different discursive frameworks that the specialists used, but was also affected by a hierarchy of power and deference based on the professional credentials of the clinicians. In the folklore of surgical culture orthopaedics is regarded as being of 'lower' status than other specialisms within the profession. The surgical consultant therefore was unlikely to defer to those

positioned lower down the professional hierarchy. Similarly the downplaying of the expertise of speech and language therapists on the grounds that their practice is not evidence-based has been used as a justification by some consultants not to involve them in the management of adult patients with dysphagia in some hospitals (Horner, 1999).

Multiple caring contexts, risk and conflict

So far we have suggested that issues of risk do not merely obtain from the positions of those involved but are continually changing; at its most simple some parents (and professionals) query the 'ecological validity' of some clinical investigations and hence the risks associated with feeding by mouth. However as we shall show the situation is rendered even more complex given that care work, and feeding, is shared amongst a range of staff in hospital and community settings (for example schools, respite care, residential care) where a range of conflicts can arise between the wishes of the parents, the advice of the doctors and those with responsibility for feeding. This we would argue provides a starting point for assessing the different ways that risk is both discursively defined and owned by clinicians as much as by carers/parents.

The management of risk, which is seen to be the responsibility of parents, is problematised in a situation where the mother becomes the risk owner and the carers the (reluctant) risk managers. For example, a child was referred for a feeding assessment by her school because her carers had experienced problems feeding her by mouth; they reported two incidents, involving choking, which raised concerns about the safety of oral feeding. Subsequently, against the wishes of the family, the carers refused to feed the child orally. The mother reported that neither the nursing staff at the residential unit where the child boarded, nor family members had experienced problems with feeding the child. The mother suggested the choking incidents had arisen because of the carers' inexperience with feeding disabled children: a case of 'new beginners'. Although a videofluoroscopy indicated that the child was at risk of aspiration, the mother expressed her reluctance to agree to a gastrostomy given the child's love of food ('it's her passion'). Importantly the consultant surgeon was happy to

respect the mother's wishes not to proceed with surgery for a gastrostomy provided she was prepared to accept the risk. In this instance he stepped outside of the biomedical discourse to respect the mother's wishes and shifted responsibility for the ownership of risk to her. Significantly, the mother's willingness to accept the ownership of risk was noted in the child's hospital records; a safeguard in the event of litigation, perhaps.

Conclusion

It is widely acknowledged that the ownership and management of risk is an important dimension of contemporary healthcare. However we have demonstrated that the positions of professional carer and patient are complex in the circumstances of paediatric care operating within the context of a multifaceted and, sometimes, contradictory clinical phenomenon such as neurodevelopmental disability and concerns about children's growth, the safety of oral feeding and need for a gastrostomy. This is particularly the case where caregivers spend prolonged periods of time feeding children, in excess of two to three hours per day in some cases (Johnson & Deitz, 1985), and which may still be insufficient time to achieve an adequate nutritional intake to sustain growth. Given the intensity and burden of feeding it is not surprising that caregivers, usually mothers, experience high levels of psychological morbidity (Sullivan et al. 2004) which is compounded by a lack of support available to parents facing the decision to proceed towards a surgical solution to their child's feeding (Craig, Scambler & Spitz, 2003). Ironically, when some parents actually request a gastrostomy tube for their child, they made be told to persevere or try harder with feeding by surgeons wishing to avoid, what some consider, a procedure associated with significant morbidity (Craig et al. 2006).

Although we initially adopted Heyman's definition of risk owner and risk manager, a central argument in this paper has been to highlight the dialectical relationship that exists between these roles. We concur with Heyman's view that the relationship between risk owner and risk manager is not therefore capable of being clearly demarcated. We would therefore also argue that it is a mistake to locate people in one position (as either risk owner or manager) given the dialectical nature of risk discourses.

While we have pointed out examples of the shifting nature of risk ownership and management in clinical encounters, these issues have wider significance following gastrostomy surgery given that training for non-parent carers, responsible for tube feeding in the community, is often deemed inadequate (Townnsley and Robinson,1999). Townnsley and Robinson (1999) in a survey of policy and practice reported that a number of local authorities only permitted nursing or medical personnel to feed children by tube; a policy which not only medicalised feeding, but prevented children from accessing education, or social care, due to the lack of trained health professionals to supervise tube feeding. Similarly families may also lose their respite care because of guidelines governing who can and cannot feed children by tube. So when mothers seemingly take on the risk manager role, and agree to gastrostomy feeding, they will now own a different set of risks of their children being excluded from education or social care.

The challenge for both clinicians and social scientists is to develop conceptual and clinical frameworks for how risk ownership and its management is constructed and shared across multiple social actors and institutional locations in the service of the child's best interests and a dispersed duty of care.

Endnotes

¹ A barium swallow is an x-ray taken to examine the oesophagus, stomach and small intestine

² Gastro-esophageal reflux disease (GORD) is a condition whereby the content of the stomach (food or liquid) moves backwards from the stomach into the oesophagus causing heartburn, regurgitation and effortless vomiting in extreme cases. This can also be aspirated into the airway.

³ The tests described here are not meant to be exhaustive and children may undergo other investigations such as 24 hour Ph monitoring, endoscopy

⁴ The term ecological validity is borrowed from research to reflect whether the methods, materials and setting of the study approximate real world contexts and hence whether findings can be generalised across different settings. It is related to external validity. See

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